

Utah
1115 PACC Demonstration
Promoting HOPE for Utah Children

FACT SHEET

Name of Section 1115 Demonstration:	Promoting HOPE for Utah Children (Promoting Hospice and Optimal palliative Efforts for Utah Children)
Date Proposal Submitted:	February 14, 2003
Date Proposal Approved:	-----
To Be Implemented:	-----

SUMMARY

On February 14, 2003, Utah submitted a proposal, “Promoting HOPE for Utah Children”, for an 1115 Demonstration to provide enhanced services to all Utah children with life-threatening conditions and their families. For the past three fiscal years, Congress has awarded funds to Children’s Health International to encourage States to develop the PACC (Program of All-inclusive Care for Children and their families) model of care. This proposal is submitted in response to those Congressional grants.

The project goal is to develop a service model for children with life threatening illness/conditions and their families in which needed care is provided in a cost effective manner and which enhances the quality of life for patients and their families. The demonstration would eliminate the requirement found in the traditional hospice benefit that an individual must be in the final six months of life, and would provide a blend of curative and palliative care and social services to the child and family unit.

An interdisciplinary team of pediatric physicians, specialists, and counselors will manage the care delivered to the child and family. Services would be coordinated and provided across all settings.

ELIGIBILITY

Children eligible for the Promoting HOPE demonstration must meet the following medical and financial eligibility requirements:

- Be age 0 – 18;
- Be diagnosed with a life-threatening condition so serious it is unlikely the child will survive childhood, as determined by the treating physician.

The State proposes to include State Plan Medicaid eligible children in year one of the program, and then expand the population of children served, in years two through five, to non-State Plan Medicaid eligible children, who will be eligible only for Package A and B Services. (See below.)

BENEFIT PACKAGE

In addition to Medicaid State Plan services (or a child's health insurance benefits) the following services are available:

- Package A Services – Administrative Services: Outreach and referral services
- Package B Services – Home-Based Supplemental Services: Palliative care consultation; Nursing and other therapeutic and palliative care; Counseling and expressive therapies; Ancillary support; Respite; Medical supplies and equipment; Pharmacy; Transportation not otherwise covered by primary health insurance plan.
- Family Choice Plan - Families may also hire and oversee their own respite or family support provider through the “Family Choice Plan” that allows the family to select a surrogate, known and trusted by the child and the family, to provide temporary relief for the primary caregiver or during a temporary absence.

ENROLLMENT PROCESS

The physician will determine medical necessity for Promoting HOPE services, by diagnosing the infant/child as having a life-threatening condition so serious it is unlikely the child will survive childhood. To secure Package A Services, a physician, nurse, parent volunteer or other member of the care team will inform the parent of the information and resources needed immediately. Thereafter, either the Promoting HOPE Outreach Coordinator or Care Coordinator will follow up with the child's family to explain the program and the options available to the family. Families then have the option to enroll in the program and secure the Package B Services.

DELIVERY SYSTEM

Package A and B services will be provided through a network of public and private programs and agencies. Referrals for program services will initiate from the Primary Children's Medical Center located in Salt Lake City since it has the greatest experience treating children with life-threatening conditions. Package A Services will be reimbursed as an administrative service. Package B Services are designed to supplement the child's health insurance benefits and will be reimbursed on a fee-for-service basis. The Promoting HOPE program expects to enroll 327 children in the course of the five years.

EVALUATION AND QUALITY ASSURANCE

The State will conduct an evaluation of the program to determine its success in meeting major program goals. The State will also implement a quality assurance plan that builds upon and expands the safeguards in place to protect the health and welfare of the participants.

BUDGET NEUTRALITY

The State is proposing to establish budget neutrality through the provision of early interventions at home, such as nursing services, thereby reducing the need for costly inpatient services. The State will also establish a sliding fee schedule for families with other health benefits to allow them access to certain non-covered Package B services.

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